EXPLORING INTERNATIONAL PRIORITIES AND BEST PRACTICES FOR THE COLLECTION OF DATA ABOUT GENDER MINORITIES

Report of Meeting
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INTRODUCTION

Robust data about gender minorities can promote knowledge, increase visibility, and better inform the development of policy that impacts gender minority people. The current lack of data collection about gender minorities internationally limits how much governments, communities, and researchers know about the existence and experiences of these communities. On June 17th, 2016, researchers at The Williams Institute at the UCLA School of Law, along with a steering committee of advisors, convened an international meeting of experts to consider the current lack of international standards for collecting data about gender minorities in official, large-scale surveys. There were three primary objectives of the meeting. These included:

- Developing a network of academics and other experts who study the collection of data about gender minorities
- Determining the desirability and feasibility of developing a set of international best practices for the collection of data about gender minorities
- Considering what an international best practices model might look like and determining what additional considerations and steps are needed before beginning to develop these best practices

The meeting was held in Amsterdam, The Netherlands, the day before the twenty-fourth Biennial Scientific Symposium of the World Professional Association for Transgender Health (WPATH), which co-sponsored the meeting. Participation in the meeting was driven largely by attendance in the WPATH Symposium, as many researchers were able to extend their attendance at the WPATH Symposium to include The Williams Institute meeting. Participants to the meeting included researchers from 12 different countries, including Australia, Belgium, Brazil, Canada, Germany, Japan, The Netherlands, New Zealand, Peru, Spain, the United Kingdom, and the United States, and several international organizations, such as Transgender Europe (TGEU), International Campaign Stop Trans Pathologization (STP), and The Asia and Pacific Transgender Network (APTN).

Participants agreed that it was important that researchers from a diversity of regions, particularly from countries in the Global South, be involved in future deliberations. We note that this report is intended to represent the discussions and recommendations of participants at the meeting and not necessarily the viewpoints of gender minority populations broadly. It is our hope that this report will serve international organizations, governments, researchers, and others in considering the need for data about gender minorities and the value of a standardized approach to collecting data about gender minorities in the form of a best practices guide.

The day-long meeting was broken into four sessions. In the third session, small groups were organized to discuss specific questions and then all participants reconvened to share ideas. The four sessions focused on:

- Review of current efforts to study and develop survey questions and other measures to identify gender minorities
- Review of current practices to collect data about gender minorities
- Discussion of the desirability, feasibility, and potential model for international best practices (small groups)
- Discussion of next steps

TERMINOLOGY

Participants in the meeting reviewed the large number of terms that refer to different aspects of gender. Throughout this report, we use a variety of terms, including "gender identity," "gender minority," "gender expression," "trans," "transgender," and others to describe distinct populations and characteristics of individuals. When we use the term "gender identity" we mean an individual's internal sense of their own gender and connection with a particular gender identity label, such as man, woman, transgender, and other non-binary gender identities. We use the term "gender minority" to refer to those whose gender identity does not match their sex assigned at birth, which includes a wide variety of gender identities, such as transgender, genderqueer, and other identity labels. "Gender minority" is a purposely broad term that allows us to consider groups of individuals whose gender identity may not match their sex assigned at birth but who may use terms other than "transgender" to describe themselves. This may be particularly relevant in nations and communities with a history of recognizing a third gender or other gender minority identities.

IMPORTANCE OF DATA COLLECTION

Participants recognized that, while there are limitations and ethical concerns about data collection, outlined later in this report, data collection was important for a number of different reasons:

DEMONSTRATING THE EXISTENCE OF GENDER MINORITIES

Data about gender minorities helps make gender minority people visible and, in turn, can reveal issues that significantly affect these communities. While some communities have a rich history of recognizing gender minorities, such as for *hijras* in South Asia, this is not the case everywhere. Gender minorities are often overlooked in cultural and political life in many countries.

DESTIGMATIZING GENDER MINORITIES

Collecting data on the lives and characteristics of gender minorities can help destigmatize these groups. A participant stated that "everyone should be able to be accounted for" and be "visible in a community." Visibility and reducing stigma can help promote the collection of additional data, foster research, and encourage services and policies to be developed to address the concerns of gender minority communities.

DOCUMENTING THE EXPERIENCES AND CHARACTERISTICS OF GENDER MINORITIES

Collection of data can provide a wealth of information about the lives of gender minorities. This information fosters greater understanding of gender minorities and allows researchers and others to identify unique experiences and disparities faced by gender minority communities. The enumeration of the characteristics and experiences of gender minorities can help provide for greater representation of community concerns in government decision-making.

INFORMING POLICY AND PROGRAMS

Data allow verifiable, empirical considerations to be incorporated into policy analyses addressing the issues affecting gender minorities and encourage additional data collection and research about gender minorities. Data collection about gender minorities allows for service providers, governments, and other institutions to tailor programs and policies appropriately to address the concerns and needs of gender minority communities. Government decisions about the appropriate allocation of resources, including public funding, are driven by data. It is important, therefore, that information about gender minorities is included in these data.

MEASUREMENT SCIENCE AND DATA COLLECTION PRACTICES

MEASUREMENT SCIENCE

Meeting participants, among whom were researchers leading efforts to empirically test the validity of measures of gender identity that can identify gender minorities, discussed current research to test and validate these measures. To inform the discussion, participants submitted published studies concerning the science of gender identity measurement that they had conducted or relied on in their own work. Thus, these studies do not represent the full extent of current efforts. These studies are listed in the Appendix.

These studies touch on a number of distinct issues relevant to gender identity measurement. One such study is presented in a 2014 report by a group of US-based researchers, called the GenIUSS group (Gender Identity in US Surveillance). The GenIUSS group was formed to analyze, discuss, and recommend measures for identifying gender minorities in population-based surveys in the United States. The GenIUSS group's recommended measures were comprised of single-item and two-step gender identity and transgender status measures.

A single-item measure uses one question to identify an individual's gender identity or transgender status. For instance, a single-item measure currently used by the US Centers for Disease Control and Prevention (CDC) in a national, interviewer-administered survey asks: "Do you consider yourself to be transgender?" If a respondent states that they do not understand the term "transgender," the interviewer provides a definition. Another example of a single-item measure can be found in the US National Inmate Survey. This question, which research has shown to be an inadequate measure for gender minorities, asks: "Are you male, female, or transgender?"

A two-step measure, however, asks survey participants to provide both their sex assigned at birth and their current gender identity. Comparing responses to these two questions, analysts can identify those whose gender identity is different from their sex assigned at birth. Current research is helping to refine the two-step measure in regard to the specific gender identity terminology used, the ordering of the two questions, and the ways in which the measure can be modified for different data collection modes.

DATA COLLECTION EFFORTS

Prior to the meeting, participants were asked to provide the Steering Committee with information regarding government efforts that they are aware of that are currently underway to collect data about gender minorities. This information was compiled and presented at the meeting, and we include this information in this section, organized by region. The data collection practices that participants submitted do not represent the full extent of current efforts. It should also be noted that data collection efforts in the United States of America and Canada are covered more comprehensively in our review because of the large number of meeting participants from those countries.

Asia and the Pacific

In 2015, Statistics New Zealand released the Statistical Standard for Gender Identity. This new standard added the term "gender diverse," alongside "male" and "female," to the current classification of gender identity for statistical purposes in New Zealand. This standard was the first in the world.

In Nepal, individuals are permitted to register a third gender designation on citizenship documents and in the national census.

In India, a third gender was recognized by the Supreme Court, and this has also allowed for government-issued IDs and other documents to recognize a third gender designation.

Europe

At the regional level, the European Union is engaged in collecting data about gender minorities. In 2012, the European Union Agency for Fundamental Rights conducted a survey of lesbian, gay, bisexual, and trans (LGBT) adults in member states and used a single gender identity question with multiple answer options (such as, transsexual, transgender, cross dresser, queer, and others) to identify gender minority respondents.

In the United Kingdom, the National Health Service England and Public Health England are examining gender identity questions for employees and health care users. The Equality and Human Rights Commission, in 2012, tested questions to determine how many individuals would be covered by the protected characteristic of "gender reassignment" under the Equality Act of 2010.

In the Netherlands, the Netherlands Institute for Social Research, which conducts large-scale surveys on social and cultural issues in the country, is currently interested in collecting data on the living arrangements of LGBT individuals. In 2016, using data from five representative surveys, the first LGBT monitor was developed to collect information on the life experiences of LGBT people and public opinions in the general population toward LGBT individuals. The monitor includes a section about transgender individuals.

Latin America

Uruguay, in 2016, started a national census for transgender persons, led by the Ministry of Social Development (MSD). Data from transgender citizens are collected through an online platform and direct outreach at MSD offices.

In Brazil, data about gender minorities is collected in a number of different ways. Mandatory reporting of data from individuals diagnosed as HIV positive includes data from transgender individuals, and reforms are being considered to distinguish transgender women from men who have sex with men (MSM) in the data. Data are also maintained about gender identity notification to police and health services providers under specific circumstances. The use of official and social names on the federal health insurance card and by federal and state institutions are also permitted, potentially providing additional sources of data.

North America

In the United States of America, a number of federal, state, and local government agencies are leading efforts to collect data about residents' gender identity. At the local level, departments of health from large urban areas have begun collecting these data. In New York, the New York City Community Health Survey includes a two-step measure, which asks sex assigned at birth and current gender identity. There are also efforts within the San Francisco Department of Public Health to collect data about gender minorities. In the state of California, legislation was passed in 2015 that mandated that several state human services agencies collect gender identity and sexual orientation data. However, there are not specific guidelines, no timelines were launched, and specific implementation is not clear. The California Health Interview Survey ran a successful pilot of potential gender identity questions, and in 2015 added a two-step gender identity measure.

At the national level, the US Office of Management and Budget led an inter-agency effort to study gender identity data collection for implementation in federal surveys. The US Department of Health and Human Services (HHS) now requires one funding program, the Ryan White HIV/AIDS Program, to provide information about transgender status in its program services reports. HHS has also required, through its meaningful use of electronic health records programs, that sexual orientation and gender identity be collected through electronic health records that are certified through the program. There are also a number of federal surveys that collect data about gender minorities. Some states include a single-item transgender status question in administering the CDC's Behavioral Risk Factor Surveillance System (BRFSS) survey. Additional states have designed their own gender identity questions. The Youth Risk Behavior Surveillance System (YRBSS) survey, the youth version of the BRFSS, has an optional gender expression measure, which is designed to assess gender non-conformity by assessing respondents' masculinity and femininity. The US National Inmate Survey employs a single-item gender identity measure that allows people to identify as male, female, or transgender. The US National Crime Victimization Survey included a two-step gender identity measure in the 2016 survey. While many of these efforts include data collection through self-reporting, there is also research underway on the use of proxy reporting that would allow an individual in a household to respond to a survey's gender identity measure for other members of that household. Proxy reporting is typically used in the Decennial Census, the American Community Survey, and the Current Population Survey.

In Canada, for the 2016 Census, Statistics Canada implemented a procedure allowing respondents to leave the census sex question as blank and to provide a written comment about their gender identity. Statistics Canada made a public commitment to analyze and release a report about those written comments. This information will feed in to the proposed round of consultation with stakeholders and experts about gender identity. A task force within Statistics Canada will be directly responsible for identifying and recommending options for measuring gender identity for Statistics Canada's social surveys.

Statistics Canada is beginning a process to expand sex/gender options for the 2021 Census. A task force has been organized at Statistics Canada to help manage this task. It is expected to result in a change not just to the census, but to all the surveys Statistics Canada administers (e.g. the Canadian Community Health Survey and the General Social Survey).

The Canadian Human Rights Commission has commissioned a mapping of all of the locations in which gender is encoded on federal documents or federal databases and how this information is shared.

DISCUSSION

During the third session of the convening, participants were asked to consider these three questions:

- Are international best practices desirable? Why or why not?
- Are international best practices feasible? Why or why not?
- What would a model look like for creating international best practices?

These topics were central to establishing the next steps for developing a best practices guide. Participants were organized into small groups to consider these questions, after which each group reported back to the full convening for further discussion.

DESIRABILITY OF BEST PRACTICES

Participants reached a consensus that developing a set of international best practices for the collection of data about gender minorities was desirable. Participants identified a number of ways in which this data collection was valuable, some of which correspond to the benefits of data collection generally.

Provide Guidance

Participants noted that advancing greater understanding of gender minority data collection can help those who are currently or planning to collect these data, but do not have prior experience with or knowledge about how best to do so. Whether these efforts are led by governments, non-governmental organizations, or independent researchers, having a set of best practices about gender identity data collection allows these entities to better design and implement new data collection efforts.

Foster Comparability

Many participants commented on the ways in which data about gender identity can allow researchers to make comparisons across different populations, both within and among countries. Comparisons such as these are important for researchers in documenting the existence of experiences related to health, education, safety, and other issues.

Government Accountability

Participants also noted that the standardized collection of data about gender identity allows gender minority communities and their allies, including supportive nations, to hold governments accountable for documenting the experiences of gender minorities and addressing their concerns. Governments, international institutions, and other organizations can use the resulting data in their own “country-to-country comparisons” in determining and prioritizing policies.

FEASIBILITY OF DEVELOPING BEST PRACTICES

Meeting participants reached a consensus that developing international best practices for gender minority data collection is feasible. In discussion, participants offered a number of issues that must be considered when developing best practices in order to produce measurements that are accurate and culturally appropriate.

Involvement of Affected Communities

Throughout the meeting, one of the matters that participants raised in a variety of different contexts was the lack of representation of particular regions amongst the participants in the meeting. Having been convened in the Global North, adjunct to a symposium constituted mostly of health professionals from Global North countries, such constituencies were heavily represented while other segments of the community, and the Global South, were not. In addition, participants noted that the general body of research on gender identity measurement and the community of researchers grappling with how best to capture gender minority populations in data collection come mainly from nations in the Global North.

It was noted by one participant that individuals engaged in studying gender minority data collection are not exclusively academics, and we should take advantage of the knowledge and experiences of individuals working in the public sector, civil society organizations, and elsewhere to inform data collection about gender minorities. While participants in this first meeting were not exclusively from academic institutions, it would be desirable to engage other groups who may be working on issues relevant to gender identity data collection.

Participants noted that, in order to develop best practices that could be applied in countries around the world, individuals from a diversity of nations and regions must be present and involved in the process. Additionally, involvement from gender minority communities in developing best practices recognizes and utilizes the knowledge of the community and necessitates consideration of their needs and priorities. Inclusion of community members ensures that recommendations for measurement will be, as one participant described, "representative of what people feel culturally." This inclusion of gender minority communities in the development of a best practices guide is central to the question of feasibility.

While many participants indicated their support for the inclusion of gender minority communities, individuals also raised concerns about potential challenges. A participant stressed the importance of providing tools and information regarding the technical aspects of measurement to help ensure that community members are able to provide informed support for data collection. Individuals should be able to recognize, according to another participant, "why we're doing this, why it's important, what are some of the terms that are going to be used." Much of the work involved in determining a measure of gender identity involves the highly technical work of reviewing the current research and identifying benefits and costs to different approaches. One participant stated that "I think it's important that we provide some kind of framework of understanding the knowledge and not just kind of throw them into the discussion. Because when these discussions become very objective, they become very objectifying." Another participant said that "concepts have to be explained to the community . . . [so that] when the population approach[es] it, they can understand the strategy of using standardized terms that group different cultural identities."

In pursuit of these goals, some members argued that this group should develop a mechanism so that individuals from gender minority communities can provide feedback on the process of developing a best practices model. One participant stated that they did not know of "a mechanism to make that happen." Another participant suggested that existing networks of gender minority communities could be used to organize and facilitate feedback from community members.

Safety of Gender Minority Communities

Participants were concerned about ensuring the safety of gender minority communities in the data collection process. One participant suggested that "as long as it's safe . . . you should be encouraging the measurement of the full spectrum of gender identity." Another participant suggested that "you can't ask if asking is going to result in further danger for the people who are being asked." Collecting data to identify gender minority individuals in an environment where gender minorities do not feel safe identifying as such would likely result in inaccurate data, another participant noted. Furthermore, the risk of non-supportive governments misusing data was also noted. With these comments, it was suggested that a statement could be included in a best practices guide that would address concerns about safety as well as the importance of encouraging measurement where appropriate.

Cross-Cultural Concerns

Participants noted that a single global approach may not be useful or successful given cultural diversity in the conception of gender, gender expressions and identities, gender categories, and terminology. Accordingly, participants considered the feasibility of regional best practices. For example, one participant suggested that in Europe, where significant work has been done on gender minority data collection, developing a regional guide for the continent would itself be an achievement. Other participants, however, felt that a regional approach would not be appropriate. One participant argued that this approach would favor some regional understandings over others, and that, for example, "within the Global North . . . the train has left the station" and a regional approach would simply mean Western practices would become the "de facto" standard for other regions.

Another participant suggested that a "bottom-up" approach to creating international best practices was more appropriate than a "top-down" approach. A "top down" approach might prioritize an international consensus, such as through the adoption of a particular approach by the United Nations or other institutions. This would encourage national-level political discussions around gender identity measurement instead of encouraging discussions at the local community level.

Participants also addressed issues of feasibility around the language used in measuring gender identity. Some participants' comments related to literacy generally, and these concerns are central to the development of questions on any large-scale population-based survey. Low literacy rates in some countries and a lack of understanding of terminology among individuals of certain age groups are important for researchers to consider.

There was also discussion of the terminology used in collecting data about gender minorities. Many participants agreed that developing best practices for identifying gender minorities in surveys could only be done appropriately when local identity terms were considered. For example, the terms "trans" or "transgender," which are used commonly in the West, may not be applicable to gender minority populations in other regions. Terms such as "travesti," "fa'afafine," "hijra," "kathoey," and "two-spirit" may be more appropriate. Similarly, participants noted that in some cultures terms for certain gender minority populations may overlap with terms used for certain sexual orientations. What is being captured with these measures, therefore, "isn't necessarily gender identity alone," one participant noted.

The process involved in determining the most appropriate terminology to use in gender identity measures was considered more fully in the discussion around what might be recommended in a best practices guide. While empirical research on the use of certain terms, such as "trans" or "transgender," exists, it was noted that "whatever we [propose] it hasn't been probably validated and tested in as many languages as we can." However, it was also noted that current limitations in measurement research should not alone discourage data collection about gender minorities.

Institutional Support

The feasibility of developing best practices may also depend on securing support from a variety of organizations and institutions. Financial assistance is an important part of that support. Some participants noted that such a large-scale effort has to be funded by a government or an international governmental institution in order to succeed. This form of support can also ensure that a best practices guide has buy-in from international institutions.

Institutional support can also provide legitimacy to a final set of best practices. In many countries, governments, in determining both whether to collect data about gender minorities and what might be an appropriate measure, "always look after an international body to be able to say . . . 'this principle is the most recognized by this organization,' " noted a participant. This sort of institutional support would lend credibility to recommendations of a best practices guide and help ensure that "this is not seen as a renegade or oppositional issue."

CHARACTERISTICS OF A BEST PRACTICES MODEL

Though the main purpose of the meeting was to determine whether a best practice model was desirable and feasible, the participants did take the next step and begin a discussion of potential characteristics of a best practices model. Specifically, participants were asked "What would a model look like for creating international best practices?" The discussion produced several sets of considerations and options for future action.

Recommendation of a Measure

Participants raised the issue of whether best practice guidelines would take the form of a single recommended measure of gender identity, a battery of recommended measures, or a process-based guide for the development of local, culturally-appropriate measures. All options received support of at least some of the participants, though the last seemed to receive support of most participants.

A process-based guideline would encourage those developing surveys and other researchers to consider the benefits and costs of different measures and, ultimately, to adopt measures that accurately reflect the identities of gender minorities in their communities. These culturally-appropriate measures are intended to be respectful of the communities in which data collection is being conducted and may ultimately provide better quality data. One participant noted that best practices should be part of "a document that grows and breathes and changes." As researchers and governments begin implementing gender identity measures in surveys and other data collection efforts, new data on the validity of specific measures in certain countries will become available. These data should guide experts in refining our understanding of best practices. Participants repeatedly noted that the root goal of a best practices guide is to identify "the best way . . . to make people's lives better and to make data collection better."

The recommendation of a two-step measure received a high level of attention in the discussion. Participants specifically considered the applicability of a two-step measure such as the one recommended for use in the United States by the GenIUSS group. One participant noted that single-item measures of gender identity do not accurately capture gender minorities and that the current body of research indicates that single-item measures significantly undercount gender minority populations compared to two-step measures. A two-step measure can also

be adapted to the cultural context of gender identities in communities where data collection will take place. However, one participant suggested that in some cultures, sexual orientation and gender identity are not independent of each other, so a gender identity question in a two-step measure may not solely identify people who are gender minorities. There was informal consensus that it was appropriate to recommend a two-step measure as a part of a process-based best practices guide. By providing best practices recommendations within a process-based framework, survey designers are given the flexibility to adapt the terminology used in a two-step measure to best fit their communities.

Inclusion and Active Participation of Gender Minority Communities

As an issue of feasibility, participants agreed that including gender minority communities in the process of determining best practices was critical. Participants recognized that a process detailing how to ensure this inclusion and active participation had to be intentionally included in a best practices guide. Being fundamental to the feasibility of developing best practices, inclusion of gender minorities should be explicitly stated as a key process in any best practices guide.

RECOMMENDATIONS

Through this convening, participants came to agreement on the desirability and feasibility of developing best practices for data collection about gender minorities. Participants also offered a number of important considerations for the next steps in developing best practices. Based on group consensus and these additional considerations, we recommend that governments and international institutions:

- **Engage in and provide support for collection of data about gender minorities and data analysis**
- **Consider the inclusion and active participation of gender minority communities in the process of supporting data collection and analysis**
- **Consider the safety of gender minorities when considering and conducting data collection and analysis**

NEXT STEPS

This convening was an early effort in the process of determining how best to encourage the collection of data about gender minorities around the world. There are a number of important next steps that meeting organizers, participants, and other stakeholders will need to take to continue this process. These include:

MAKING DETERMINATIONS REGARDING BEST PRACTICES

This meeting generated agreement among participants about the desirability and feasibility of establishing best practices, but it also raised many important questions regarding how best to approach developing those best practices and what, ultimately, may be included in them. Future convenings will need to make decisions on these issues.

SECURING FINANCIAL SUPPORT

The process of developing international best practices is costly. Future efforts may involve significant international travel, in-country or in-region meetings, local testing, and the time of experts and government officials. It may also be important for international governmental institutions to have a financial stake in these efforts by providing funding for this work.

SECURING ORGANIZATIONAL SUPPORT

The implementation and appropriate use of best practices is as important as the development of a best practices guide. The support of international institutions, professional associations, and governments will be critical to securing quality data that can be used to inform the decisions of policymakers and experts. National governments often look to guidance adopted and recommended by these organizations, such as the United Nations Statistics Division, before implementing changes to their own efforts. Gaining this support will be important for future efforts.

ESTABLISHING A NETWORK OF RESEARCHERS

One of the objectives of this meeting was to bring together experts studying and supporting the collection of data about gender minorities around the world and establish a network to facilitate and collaborate on this work. The process of developing and enlarging a collaborative network of international colleagues, including broader representation of colleagues from the Global South, will be important for maintaining this initiative.

APPENDIX

The literature in this appendix was originally provided by meeting participants who were asked to recommend publications relevant to the topics to be discussed at the convening for inclusion in a final report. The following citations include English language publications only and do not include publications beyond those provided by meeting participants.

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